Delivering high quality end of life care for people who have a learning disability

Resources and tips for commissioners, service providers and health and social care staff

How to use this guide

Under each ambition, (see links below in contents page) those commissioning, providing or delivering care to people with a learning disability at the end of their lives will find 'top tips', resources and good practice examples to support the achievement of each ambition for people with a learning disability.

It is important to view all people holistically when providing end of life care. People with a learning disability, like other members of society, will have a range of characteristics that may inform their needs and expectations in relation to end of life care. For example, expectations about end of life care may be shaped by someone's ethnicity, faith, values and/or other beliefs. It is important not to make assumptions about the care the person needs because of their learning disability diagnosis. Rather the aim should be to effectively engage with individuals, their families and carers to ascertain their individual needs, expectations and wishes.

Please click on the links below to go directly to the relevant page in this document.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please call 0300 311 22 33 or email england.contactus@nhs.net.

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About this guide

This 'top tips' guide aims to support commissioners, providers and clinicians to reduce inequalities in palliative and end of life for people with a learning disability, focusing on 'The Ambitions for Palliative and End of Life Care'[1]. These six ambitions provide a framework for national and local health and care system leaders to take action to improve palliative and end of life care. Developed by 27 organisations across the palliative and end of life care system, these ambitions set out what high quality palliative and end of life care looks like. The ambitions call on leaders from every part of the health and care system, and the wider community, to put the framework into practice.

This 'top tips' guidance has been developed by NHS England in association with the Palliative Care for People with Learning Disabilities (PCPLD) Network[2]. The development process involved consultation with Public Health England and a range of commissioners, providers and professionals working within palliative and end of life care and learning disability settings. People with lived experience have also helped us to develop the guide. Further details of the development process can be found at the end of this document.

Defining palliative and end of life care

'The Leadership Alliance for the Care of Dying People' (2014) produced a glossary of terms that includes helpful definitions of palliative and end of life care. You can find the full glossary in 'One chance to get it right', published on the gov.uk website (https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations). A summary is provided below.

Palliative care

'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'[3].

End of life care

'Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days)'.[4]

Defining a learning disability

Individuals with a learning disability (internationally referred to as individuals with an intellectual disability) are those who have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;

- a significantly reduced ability to cope independently (impaired adaptive and/or social functioning), and;

- which is apparent before adulthood is reached and has a lasting effect on development'. NHS England (2015)[5]

To meet the criteria for having a learning disability, all three categories must be met. Having a learning disability has previously been identified as an Intelligence Quotient (IQ) score in the region of 70 or below, but IQ alone should not be used to determine the presence of a learning disability. It is not appropriate to use a 'cut off' figure of 70, as the results of a recognised IQ test require skilled interpretation. There should also be significant difficulties in adaptive and/or social functioning, for example in relation to conceptual, social and practical skills (such as language, interpersonal skills and activities of daily living).

Inequality in palliative and end of life care for people with a learning disability

The extent and impact of inequalities on the health of people with a learning disability have been well-documented over the years. Research indicates that people with a learning disability are three times as likely to die early than the general population[6]. They are also more likely to experience poor general health, and to have high levels of unmet physical and mental health needs[7].

Health inequalities for people with a learning disability also extend into palliative and end of life care. In May 2016 the Care Quality Commission (CQC) published a thematic review[8] into inequalities in end of life care. The review identified that 'people from certain groups in society sometimes experience poorer quality care at the end of their lives because providers do not always understand or fully consider their needs'[9]. It identified people who have a learning disability as one such group. The Confidential Inquiry into premature deaths of people with a learning disability (CIPOLD)[10] found that for many people with a learning disability, who were dying, end of life care was not coordinated and the support for the person and their families could have been improved. It also identified that people with a learning disability were less likely to have access to specialist palliative care services and opioid analgesia than a comparison group of people without a learning disability. Other research has suggested that hospice, palliative care and end of life care professionals report limited contact with people with learning disabilities and a lack of confidence in working with this group and understanding their needs[11].

Although people with a learning disability still die at a younger age than the general population, the median age of death for people with a learning disability is increasing[12][13]. Therefore, the ageing process seen in the general population, including the onset of frailty, will become more apparent in the population of people with a learning disability as people live for longer, which may alter their end of life care needs.

Inequalities in care and the needs of BME communities

'Valuing people Now'[14], recognised that people with a learning disability from black and minority ethnic groups and newly arrived communities and their families often face 'double discrimination'. These individuals may experience insufficient and inappropriate services caused by: 'policy and services which are not always culturally sensitive; wrong assumptions about what certain ethnic groups value; language barriers[15]; and discrimination'. Providing a culturally sensitive service is crucial to an appropriate end of life service. In end of life care, it is particularly important to ensure that the service is culturally sensitive and takes account of the needs of the person with a learning disability. Whilst no assumptions should be made about whether the person with a learning disability is a person of faith, it will be important to assess if they are a person of faith and whether this informs their expectations about end of life care. These considerations will inform all six ambitions set out in this document.

Ambition 1: Each person is seen as an individual

'I, and the people important to me, have opportunities to have honest, informed conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what is possible.'

TOP TIP:
Support people with a learning disability to develop their awareness about death and dying

Why is this top tip important?

Sometimes those involved in the care of people with a learning disability such as health and social care professionals, families and friends, believe they are protecting the person by not including them in conversations about death and dying. This is not the case. People with a learning disability, just like everyone else, should have the opportunity to participate in conversations about death and dying. Understanding that death and dying are a part of normal life can really help people with a learning disability be more prepared for the deaths of loved ones, and ultimately for their own death.

'It is extremely important [to know about death] from an early age. It helps you to process it easier and it's important because it's a natural thing'.

GRASSroots group

'There can be a tendency by professionals and families to 'jolly people along' rather than allow feelings of sadness to surface. This can block conversations about death, as well as expressions of sadness. It can really help people with learning disabilities to realise that it is OK to feel sad and that they are not alone in their feelings of distress'.

Dr Irene Tuffrey-Wijne, Associate Professor in Intellectual Disability and Palliative Care

How to put the top tip into practice?

- Encourage discussions about death and dying at all times, rather than waiting until a person has a terminal condition.

- Support staff working with people with a learning disability to feel confident in having these conversations.

- When people die, talk about it, for example, personalities in the media, staff, friends, family, soaps/TV series'.

Tools and resources

- 'Breaking bad news to people with intellectual disabilities; a guide for carers and professionals'. Dr Irene Tuffrey-Wijne. Breaking bad news website - (www.breakingbadnews.org/tools/)

- 'We Are Living Well But Dying Matters'. A film produced by CHANGE for Dying Matters and the National End of Life Care Programme. Dying Matters website - (www.dyingmatters.org/page/were-living-well-dying-matters)

- 'Dying to Talk' A series of short DVDs to help people with a learning disability think and talk about dying. Sunshine website - (http://sunshinelgd.org.au/about-us/research/)

Good practice example

'In Hertfordshire, adults with learning disabilities of any health status are invited to attend 'Leaving Life' workshops. These are facilitated by community learning disability nurses, support workers and any staff from within the multi-disciplinary team who would like to take part. They are very slow paced lasting for approximately five hours with discussions taking place around individual's end of life wishes (should they get very ill) and the creation of a one page profile that lists 'what's important to me', 'how best to support me' and 'how I would like to be thought of'. The focus is not so much about funeral arrangements as about how and where people want to be cared for. The workshops end with people creating their 'Bucket List' of things they would like to do before they die (or get really ill). 1:1 or 1:2 support is provided so that key information is not missed and sensitivity can be applied more effectively'.

Barbie Sayers, Community Learning Disability Nurse, Hertfordshire

Involve families/friends/supporters and the person's usual paid carers as partners in care

Why is this top tip important?

In order to provide appropriate end of life care that meets the person's needs, it is essential to involve the person's family and usual carers as part of the team. There is strong evidence[16] that people with a learning disability get poorer quality end of life care, and are at risk of premature death, if professionals do not listen to the carers. At the same time, it is important to provide carers with plenty of support.

Jean Willson OBE shares her daughter Victoria's experience of end of life care and the importance of involving family, to help improve end of life care for people with a learning disability:

'Together, her family, her circle of friends, Centre 404 the service provider and the palliative care team gave an outstanding end of life support to Victoria. Death is the thing you only have one go at, so you need to get it right – so think family! In life, most family carers share a very special bond with their daughters and sons, brothers and sisters, mothers and fathers, nephews and nieces who have a learning disability. So, for the end of life for a person with a learning disability it is vital that the family plan and share the death of their loved one. If they wish, they should be involved at every stage, including developing the Advance Care Plan' (see following tip).

How to put the top tip into practice?

Jean's 'top tips' for improving working with family carers include:

- **Explain what is going to happen at each stage.** It was important to us to understand the process of dying and knowing what to expect or how to participate. Some family carers may not be familiar with understanding the dying process. Explain the process of what happens to the body when dying in a simple way, and what things you can do together.

- **Use the person's circle of friends.** Many people with a learning disability have a group of people, including their family, to help make decisions about their life. Victoria had had the same circle for over 10 years. This group of people will know the person well, and have their best interests at heart. They will offer suggestions of things to do and practical help.

- **Involve family members in the team and understand their ways of working.** Some of the people involved with supporting Victoria were not familiar with our way of working. This presented challenges. We actively listened to each other; were honest, open-minded and prepared to work together. We had weekly telephone calls with the team leader and face-to-face meetings with the palliative team when necessary.

- **Being a positive household.** We worked hard at having a positive and relaxed atmosphere in the house. We introduced tea parties; invited guests, played jolly music and laughed a lot. We became innovative in changing Victoria's bedroom into a wonderland with fairy lights and sari material, and in bringing the world to her. This was a shared house, so it was important that her flatmate continued her life as much as normally possible.

- **Saying goodbye.** Time permitting, family, friends, neighbours; present and past staff, may want the opportunity to come and say goodbye in person. This presented a particular challenge, as the other tenant and her family needed to agree with what we were doing. We did check this out with the other tenant's family and her circle of friends. We tried to be very sensitive to her flatmate and her lifestyle, and many things took place in Victoria's bedroom. People very much appreciated the opportunity to say goodbye in their own way, including her flatmate.

- **Funeral arrangements.** We had nearly two years to make arrangements for a service and funeral. Many families find this very hard and challenging. It is very important to get families talking and working together on this. Although the family introduced their plans, at every stage the team leaders were part of the planning. This included the service, speakers, music, flowers, cremation and people coming. We also included what would happen to Victoria's things.

Tools and resources to support the involvement of families

- Together Matters has produced two 'planning ahead' guides; one for family members and one for people with a learning disability. They are available on the Together Matters website - (www.togethermatters.org.uk/resources-and-information/)

TOP TIP:

Support people to engage in Advance Care Planning (ACP) (ensuring mental capacity is considered). If the person is assessed as not having mental capacity to create an ACP it is still very important to ensure the person can express their end of life preferences and participate in personalised care and support planning

Advance care planning (ACP) is a process of discussion between an individual and their care providers irrespective of discipline. The difference between ACP and planning more generally is that the process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.

With the individual's agreement, discussions should be:

- documented

- regularly reviewed

- communicated to key persons involved in their care.

Examples of what an ACP discussion might include are:

- the individual's concerns

- their important values or personal goals for care

- their understanding about their illness and prognosis as well as preferences for types of care or treatment

- the option of a personal health budget where appropriate.

(Department of Health, 2007, revised 2008).

Why is this top tip important?

It is important that everyone, including people with a learning disability, are offered opportunities to engage in ACP. Even if they do not have the mental capacity to fully participate in advance care planning discussions, the person should still be supported to identify and share their choices about end of life care. This should be documented as part of their personalised care and support plan[17]. Just like everyone else, being able to make choices about current and future end of life care and ensuring that those involved in end of life care are aware of these choices can really help improve the quality and experience of care for the person.

Mental capacity and involvement in planning care

If a person is assessed to lack mental capacity[18] to make a certain decision in relation to their end of life care, it is still important to do everything possible to enable honest conversations and involve the person as much as possible in planning their care. It is also important to include significant others in the planning such as family, usual carers/supporters and friends. Information about the Mental Capacity Act for people with a learning disability and their carers can be found on the Mencap website - (www.mencap.org.uk/advice-and-support/mental-capacity-act)

How to put the top tip into practice?

- The person with a learning disability must always be at the heart of any decision making.

- Start the conversation as early as possible. Conversations should be ongoing.

- Although ACPs are often initiated when a person has been given a diagnosis of a life limiting condition, the ACP process can start earlier, for example following attendance to a 'leaving life' workshop or by making use of ad hoc opportunities to talk about death and dying.

> *'The doctors can advise, but not tell you what to do. I should be able to have a family meeting and say what I want to happen'.*
>
> **Person with a learning disability, GRASSroots group**

- Have honest discussions with the person approaching the end of life in a way that is meaningful for them.

- Remember that people with a learning disability may express their views in non-verbal, unconventional ways. Consider that people may also have communication requirements associated with having other disabilities. The Accessible Information Standard (https://www.england.nhs.uk/ourwork/accessibleinfo/) provides information on how to meet these needs, and those who know the person well may also be able to help with communication.

- There may be communication requirements where English is not someone's first language and/or the person with a learning disability and/or their family members or carers do not speak English at all. It is important to ensure that relevant interpretation and translation support/services are in place.

- ACP should be adapted to work for the person with a learning disability, supported by a range of different formats. This could include easy read materials, videos and/or pictures.

- When documenting the conversation it should be in a format that the person with a learning disability can understand, contribute to and keep.

- Difficulties arise when despite ACP discussions having taken place, GPs or other healthcare professionals have no access to any documented discussions. It is therefore equally important to save the ACP electronically, sharing it with the relevant healthcare professionals including the GP and with the person's family or usual care staff who are part of the team. The ACP should also be coded and highlighted in the person's GP record and the Summary Care Record (SCR) function turned on.

- Ensure the person themselves is included in multi-disciplinary discussions to plan end of life care.

- Work with learning disability liaison nurses within hospitals and in the community to support engagement of the person in the ACP process. Language and translation should be taken into account where necessary.

Tools and resources

- 'Books beyond words' pictures free to download from the Beyond Words website - (http://app.booksbeyondwords.co.uk/webapp/subcategory?id=7&cid=1)

- 'Some good ways to communicate with people with very complex needs' leaflets available from the Easy Health website - (www.easyhealth.org.uk/content/some-good-ways-communicate-people-very-complex-needs)

- 'Nottingham Advance Care Plan. Easier Read Version' and 'My end of life plan' Nottinghamshire Healthcare NHS Trust, available on the Dying Matters website - (www.dyingmatters.org/gp_page/end-life-care-adults-learning-disability)

- 'End of life support plan', developed by Certitude and available on the national archives webpages - (http://webarchive.nationalarchives.gov.uk/20160704190619/https://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=340)

- 'Making it work: Shared decision-making and people with learning disabilities' available on the Royal College of Nursing website - (www.rcn.org.uk/about-us/policy-briefings/pol-4112)

Good practice example

'Victoria's plan was written from both the wishes of the family and a 'best interests' medical decision. Victoria no longer had the capacity to make any decisions about her care. This plan was written by the team and it enabled joint action to take place at every stage. It became a very useful resource, guide and comfort'.

Jean Willson, OBE, talking about her daughter's end of life care

TOP TIP:

Remember bereavement support for those left behind is an important part of palliative and end of life care

Why is this top tip important?

'Caring for the person as an individual means understanding and bringing sensitivity to the need to support their unique set of relationships with family, friends, carers, other loved ones and their community. Providers of palliative and end of life care must seek to support this network by helping them to help the person who is dying. Such help includes supporting them in their own preparation for bereavement. This support must be available, sensitive and tailored to the context of their own needs, and their individual lives'

The Ambitions for Palliative and End of Life Care (2015)

> *'Someone may have severe and multiple disabilities, but they still know that the person isn't there anymore'.*
>
> **GRASSroots group**

> *'It's important people know they aren't here anymore but we can still think about them'.*
>
> **GRASSroots group**

How to put the top tip into practice?

Remember that there are a number of people who will be affected by bereavement after the death of a person with a learning disability.

For example:

- Family and friends; we often forget that as well as losing a loved one, family members may also experience loss of their caring role which may take significant adjustment.

- Paid staff such as those delivering residential care or domiciliary care.

- Friends and fellow residents with whom the person with a learning disability has lived or been close to.

For people with a learning disability who are bereaved:

- Be honest and prepared to sit and talk to people (including those with non-verbal communication) and use methods of communication most appropriate for the individuals (language, photos, books).

- Remember that the person may feel sad; a common reaction to loss. These feelings may need time to manifest.

- It can be helpful to encourage the person to remember times spent with the person who has died and the experiences they had shared 'Do you remember the time when...?'

- Someone with a learning disability may need more than one conversation to fully understand and accept what has happened.

- If staff feel sad and upset they shouldn't hide these feelings. This is a normal reaction to grief. When staff express their own feelings this can help the individual with a learning disability express their own feelings.

- The person is likely to need support to continue with their normal daily lives whilst trying to adapt to living without their friend/family member around them.

- Making a memory box, message tree, photograph album with the person can help them remember the person who died.

- Be aware that grief responses may be delayed, or may be expressed in unconventional ways.

'Going to the funeral is very important. Once a person has taken their final journey, you need to decide if you are going to the funeral or not. It's a question to think about! That's if you are even invited! Sometimes your family or carers decide that you shouldn't go to the funeral. That's wrong. From the family's perspective, they want to protect the person. The problem is, if the person wants to go to the funeral, but if the parents say no, it's very difficult. They don't have the right to make that decision. It's really, really important. Even if the person has severe and multiple disabilities, they still have feelings and emotions inside. They may know [that someone has died]. There is a way that they know. I don't know how, but they do know it inside'.

GRASSroots group

For advice around general bereavement support please see:

- Cruse Bereavement Care (www.cruse.org.uk/)

- The National Bereavement Alliance (www.nationalbereavementalliance.org.uk)

- Marie Curie (www.mariecurie.org.uk/help/bereaved-family-friends)

- Hospice UK (http://www.hospiceuk.org/what-we-offer/clinical-and-care-support/bereavement)

- Macmillan (http://www.macmillan.org.uk/information-and-support/coping/at-the-end-of-life/coping-with-bereavement)

- Dying Matters (www.dyingmatters.org/page/coping-bereavement)

Tools and resources

- 'Supporting people with disabilities coping with grief and loss' An easy-to-read booklet, available from Easy Health - (http://www.easyhealth.org.uk/sites/default/files/SUPPORTING%20PEOPLE%20WITH%20DISABILITIES%20COPING%20WITH%20GRIEF%20AND%20LOSS.pdf)

- 'Let's talk about death' for bereaved adults with a learning disability. Available from Down's Syndrome Scotland - (www.dsscotland.org.uk/resources/publications/for-parents-of-adults/)

- 'Caring for someone with an illness they will probably die from' Marie Curie easy read guides - (https://www.mariecurie.org.uk/help/publications/easy-read-booklets)

- 'Guidance for bereavement needs assessment in palliative care' Second edition. Available from Hospice UK - (http://www.hospiceuk.org/what-we-offer/clinical-and-care-support/bereavement)

- The PAMIS bereavement pack. Available from the Promoting a More Inclusive Society (PAMIS) website - (http://pamis.org.uk/resources/bereavement-and-loss/)

- Books beyond words on bereavement. Paperback books available from the Beyond Words website - (https://booksbeyondwords.co.uk/book-sets/bereavement-mini-set)

- 'Grief and loss when someone dies' Macmillan easy read booklet - (https://be.macmillan.org.uk/be/p-23291-grief-and-loss-when-someone-dies.aspx)

Good practice example

'Staff at a local care home were trying to find ways to comfort Sarah, a resident who was grieving for a fellow resident, Tom, who had recently died. Sarah had no verbal communication and so the carers were unsure about how much she understood about where Tom had gone. They got a cushion made up from Tom's favourite jumper which seemed to relieve Sarah's distress as she often sat hugging it'.

Louise Jenkins, Strategic Liaison Nurse for Secondary care and Tertiary care, Hertfordshire

'Joseph lived in a group home with three other people with learning disabilities, which was part of a wider community of local homes, where he had many friends with and without learning disabilities. Everyone knew Joseph was dying, and many of his friends came to see him. He died peacefully under the care of the local hospice. During the days that followed, we talked a lot about Joseph. The night before the funeral, Joseph's body was brought back to the house in an open coffin, and everyone who wanted was able to spend some time with him. In the room next door, around 80 people had gathered to share "Joseph stories" together, to laugh and cry and pray together, sing his favourite songs and watch a slide show of his life. Many people, including those with learning disabilities, were involved in organising the funeral. Symbols, photographs and props are used to remember him year after year including Joseph's colourful waistcoats!'

Dr Irene Tuffrey-Wijne, describes what happened when her good friend Joseph died (not his real name) at the L'Arche communities. Further information can be found on the L'Arche website. (http://www.larche.org.uk/)

Ambition 2: Each person gets fair access to care

'I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life'.

'There is a collective responsibility for all involved in the commissioning and provision of end of life care to put right' the inequality 'of access to palliative and end of life care for those with a learning disability'.

The Ambitions for palliative and end of life care (2015)

TOP TIP:
Parallel planning in commissioning is essential, considering:

- **people with a learning disability when commissioning end of life care**

- **end of life care when commissioning learning disability services**

Why is this top tip important?

If commissioning happens in silos, the needs of people with a learning disability at end of life may be missed.

How to put the top tip into practice?

- Ensure that when commissioning end of life services the needs of people with a learning disability are considered.

- Ensure that when commissioning learning disability services, their end of life care is considered as part of the whole person's care.

- When commissioning these services consider the use of local/voluntary/third sector services as well as NHS and social care services.

If a person moves into a different environment from their own home, for example, from a supported living environment to a hospice or hospital, the supported living provider will continue to play a role in end of life care before, during and after the transfer. This needs to be considered in commissioning. When a person moves to a hospice or hospital for end of life care, the supported living provider engages in a process of assessment during this transfer. To provide high quality end of life care, both services often need to undertake additional work to assess and support the person before, during and after the move. The previous provider also supports the persons circle of support (friends, family and staff) after the person has died. However, this type of care is not often commissioned and therefore does not incentivise providers to deliver the high quality care required.

Many people with a learning disability and/or autism already have the right to a personal budget for social care or a personal health budget for NHS Continuing Healthcare (or children and young people's continuing care). This includes people receiving end of life care. Mitchell's story (https://vimeo.com/13510729) shows how his personal health budget helped build relationships with healthcare professionals that enabled him to not only lead a good life, but also experience a good death.

More information about putting personal health budgets into practice for people with a learning disability is available on the NHS England website - (https://www.england.nhs.uk/personal-health-budgets/personal-health-budgets-for-people-with-learning-disabilities/)

Resources

- 'Commissioning person centred end of life care. A toolkit for health and social care professionals', available from the NHS England website - (https://www.england.nhs.uk/wp-content/uploads/2016/04/nhsiq-comms-eolc-tlkit-.pdf)

TOP TIP:

To effectively plan for the level of need and allocate appropriate resources, commissioners should make use of population data and learning disability mortality trends

Why is this top tip important?

In order to ensure 'fair access to care' commissioners need to allocate enough resource to end of life care for people with a learning disability. Population data and mortality trends within this population help commissioners identify the number of people with a learning disability who will require end of life care in their area, helping to ensure sufficient resources are allocated.

How to put the top tip into practice?

Commissioners can use the resources below to estimate the number of people with a learning disability requiring end of life care in their area and consider how their needs will differ to those of the general population's end of life care needs.

Resources

- The best up-to-date source of information about death rates in the population with learning disabilities is the regularly updated compendium 'People with Learning Disabilities in England' which currently covers half of the country (https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england-2015.) Produced by Public Heath England.

- Detail on the data in the above report can be found at NHS Digital's 'Health and Care of People with Learning Disabilities' webpage (http://content.digital.nhs.uk/article/7543/Health-and-Care-of-People-with-Learning-Disabilities). Aggregated data on key health issues for people who are recorded by their GP as having a learning disability, and comparative data about a control group who are not recorded by their GP as having a learning disability can be found on this webpage. The most recent report is 'Health and Care of People with Learning Disabilities: Experimental Statistics: 2015 to 2016' (http://www.content.digital.nhs.uk/catalogue/PUB23781).

- NHS Digital's 'Power BI interactive report' (http://content.digital.nhs.uk/article/7543/Health-and-Care-of-Peoplewith-Learning-Disabilities) enables commissioners to create local reports by CCG area around the following indicators; the percentage of people with a learning disability receiving palliative care (as recorded by GP) and the number of patients ending their GP registration by death during the year, where the patient had a learning disability diagnosis. The Power BI tool also provides age-specific death rates. The tool currently covers 50% of GP practices.

- 'Health and Care of People with Learning Disabilities' webpage on the NHS Digital website includes the summary report on the first year of data and describes the dataset and each of the major components. The page gives links to all of the annual datasets available. It also gives links to a report in Microsoft Power BI. (http://content.digital.nhs.uk/article/7543/Health-and-Care-of-People-with-Learning-Disabilities.)

- Public Health England's 'Learning Disability Health Profiles' (also known as 'fingertips') provide a range of data about people with a learning disability at local authority level. The profiles can be used by commissioners and health professionals when making decisions about services for people with learning disabilities - (http://fingertips.phe.org.uk/profile/learning-disabilities)

- Article written by Glover et al on Mortality in intellectual disability in England[19](2017) (www.endoflifecare-intelligence.org.uk/view?rid=999) provides:

  - A breakdown of deaths per ICD10 (http://www.who.int/classifications/icd/en/) chapter of underlying certified cause of death, for a four year period. This is likely to be helpful in anticipating end of life care needs (table 3, page 7)

  - Information on age/sex specific death rates for recent years (table 2, page 6)
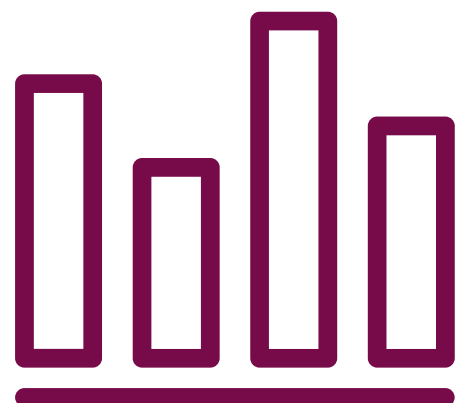
TOP TIP:

When commissioning supported living services for people with a learning disability, ensure providers can deliver continuity of care throughout the person's lifetime, and include this specification in commissioning contracts

Why is this top tip important?

The government's end of life care 6 point commitment[20] includes supporting people who are dying to make choices. These choices may range from preferences about current treatment, care and support, to plans about future care, including preferences about where they wish to be cared for, and to die. Any person, with or without a learning disability, should be supported to consider their choices and make these known.

Commissioners need to ensure that people with a learning disability, like the general population, can be supported in the whole range of choices relating to their treatment, care and support at the end of life. This includes the ability to be cared for in their own home and to die there if that is what they wish. To ensure equitable end of life care for people with a learning disability, care providers need to be able to support people with a learning disability at end of life, wherever the person lives. This includes access to specialist palliative care advice and support. It is also important to recognise that care needs may change as time progresses, especially towards the end of life. If the person's home (e.g. in supported living arrangements) is not equipped to support their care needs, a move may be difficult to avoid, even after every effort has been made to facilitate living, and dying, at home.

How to put the top tip into practice?

- In order to make this choice an option for people with a learning disability, and therefore have equitable access to end of life care, supported living environments need to ensure they can provide continuity of care throughout the lifetime, including at end of life. This should be included in commissioning contracts.

- To support people with a learning disability at end of life, care providers will need to:

  - support their staff to develop their skills to become competent in end of life care

  - provide a physical environment that can support end of life, including access to medicines and equipment

  - provide access to specialist palliative care advice and support when required.

- Providers should engage in regular monitoring and audit to ensure that the needs of people with a learning disability at end of life are being met.

- A locally agreed position not to move people unless absolutely required or requested can also be helpful. Strategic alliances will help smooth the path for many people if 'in principle' agreements are made early on. This can also help commissioners and providers with financial and operational planning.

TOP TIP:

Identify those people with a learning disability, who are in their last year of life, as early as possible

Why is this top tip important?

If we do not identify people who are dying, we lose the opportunity to provide the person with the best possible symptom management to achieve good quality care, and the opportunity to enable the person and those close to them (family, friends, carers) to plan for their end of life care can be curtailed or missed.

Dr Stuart Todd from South Wales University describes current research looking at identification and explores some possible conclusions:

'Our data on 240 representative deaths of people with a learning disability really highlights that people with a learning disability are less likely to experience an expected death (in our terms a death is expected when staff had expected it to happen 3 months or more before the death). This is really quite important because it suggests there is perceived lower level of need for end of life care in this population. Of course it begs the question – could more of those deaths have been expected and why were they not expected? It might be that the mortality profile in this population is really different – or it might mean that illnesses were not identified as life threatening soon enough (such as late diagnosis). What was concerning is that the deaths of older people with a learning disability were the least expected even though at this age death was more probable - so there is a possibility that general and gradually but progressive health decline, suggesting death is more imminent or likely, might not be identified. We are also planning a more detailed study of how expectedness is constructed. However, we wonder if care staff had been asked to ask themselves such the question, "would I be surprised if this person with a learning disability died within the next 6 months? and if the answer was 'no I would not be surprised' then what becomes interesting is what should happen next?'[21]

How to put the top tip into practice?

- Using the 'surprise question'. Asking 'would you be surprised if this person died within the next year' is a common question asked by clinicians in the general population to help identify if a person could be in their last 12 months of life.

- Tools that help identify people who are dying in the general population are not always suitable for people with a learning disability.

- Using the 'POLE' (Probability Of Life Expectancy) tool, developed by St Anne's Community Services in Huddersfield to support the identification of people who are dying (see 'good practice example below). (http://www.st-annes.org.uk/wp-content/uploads/2015/10/5.-End-Of-Life-Care-POLE-Tool-v3-SINGLES-29_01.pdf) (http://www.st-annes.org.uk/wp-content/uploads/2016/02/6.-End-Of-Life-Care-POLE-v3-Leaflet-29_01.pdf)

- When people are identified as being at the end of life, ensure health and social care commissioners are aware. This is important if funding streams change due to Continuing Healthcare (CHC) eligibility.

- Identifying a person being at 'end of life' is a clinical decision. However, be aware that social care staff may be in a strong position to identify those likely to die and may have this information before palliative care staff and health commissioners.

Good practice examples

'The team developed the *'POLE (Probability Of Life Expectancy) which encourages staff to assess health care needs well before the need for end of life care planning. POLE guides staff to be clear about what being 'in optimum health' means for each individual, and think about possible health conditions people may develop, so they can be vigilant for changes and take advice quickly if concerns are raised'.*

Catherine Wood, Business Development Manager, St Anne's Community Services

Following implementation of the tool the team noted real improvements to their end of life care delivery. Staff feel more confident, and have more open and honest conversations with people with a learning disability and their families. Sessions for families on end of life care and death and dying has moved from being a taboo subject to one that is openly talked about and planned for. You can read more about the team on the PCPLD website - (http://www.pcpld.org/linda-mcenhill-award/2015-winners/)

TOP TIP:

Identify and create the reasonable adjustments needed to ensure people with a learning disability can access the end of life care they need - a legal requirement under the Equality Act 2010

Why is this top tip important?

Under the Equality Act (2010) in England, all providers including public sector organisations are required to make reasonable adjustments if a provision, criterion or practice places a disabled person at a substantial disadvantage compared to people who are not disabled. The duty to make reasonable adjustments may therefore require providers to adjust the ways they provide care so that disabled people, including people with a learning disability, are not disadvantaged. Public sector organisations, and other organisations that exercise public functions, are also subject to the Public Sector Equality Duty. This duty requires public bodies in exercising their function, and other organisations exercising public functions, to give proper or due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations between those who have a protected characteristic and those who do not. These legal requirements mean that public sector organisations need to be proactive; both anticipating the adjustments likely to be needed and responding properly to requests for reasonable adjustments as they are required. In addition, public bodies and providers should have systems in place to enable them to assess and monitor the quality of their services in relation to their ability to make reasonable adjustments to individuals with a learning disability at end of life.

Deciding on the most effective adjustments should always involve the person with a learning disability, and, if indicated, those that know the person best. The types of adjustments that should be considered may relate to the environment, ways of providing a service, and the skills and attitudes of staff, providing aids and adaptions and/or making changes to physical features.

How to put the top tip into practice?

• Don't assume a carer/supporter is the person's usual carer. Always ask if somebody else other than their usual carer/supporter is supporting the person during an end of life care appointment/episode as this supporter may not have the most up to date information about what reasonable adjustments are needed.

• Ask the person and their usual carers/supporters what kind of reasonable adjustments are needed and ensure these are recorded (think end of life planning section in the GP Health Check Action Plan, Summary Care Record (SCR) and Electronic Palliative Care Coordination Systems (EPaCCS) - see ambition 4). For example, a need for easy read information, whether home is the preferred place of care and treatment, a need for extra time.

• Encourage the use of personal one-page profiles which will help staff who are unfamiliar with the person (for example hospital staff) to quickly get to know the most important things about the person.

• Provide staff training around providing end of life care to people with a learning disability and considering reasonable adjustments in this process (see ambition 5).

Resources:

A number of reports highlight the inequality people with a learning disability face around end of life care and provide recommendations to reduce inequalities.

These include:

- 'Recognising the importance of physical health in mental health and intellectual disability. Achieving parity of outcomes', British Medical Association - (https://www.bma.org.uk/collective-voice/policy-and-research/equality/achieving-parity-of-outcomes)

- 'Making reasonable adjustments to end of life care for people with learning disabilities' Public Heath England - (http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/gsf.php5?f=312967)

- 'Report of the Confidential Inquiry into premature deaths of people with learning disabilities' Bristol University - (www.bristol.ac.uk/cipold/reports/)

- 'Confidential Inquiry into premature deaths of people with learning disabilities' (CIPOLD) film. Available on Youtube - (www.youtube.com/watch?v=hQXzcDbaVxc)

- 'People with a learning disability: A Different Ending: Addressing Inequalities in End of Life Care' (2016) Care Quality Commission - (www.cqc.org.uk/content/different-ending-end-life-care-review-0)

- Learning Disabilities Mortality Review (LeDeR) Programme Bristol University - (www.bristol.ac.uk/sps/leder/)

The Learning Disabilities Mortality Review (LeDeR) Programme supports local areas to review all deaths of people with a learning disability aged four years and over. This will provide evidence about the service improvements needed to support people with a learning disability at the end of their life.

TOP TIP:

When commissioning learning disability services, consider dementia

Why is this top tip important?

People with a learning disability, especially people who have Down's Syndrome, are at increased risk of developing dementia as they age, compared to the general population. This also has implications for end of life care provision as we are increasingly likely to see people with a learning disability and dementia requiring end of life care. This may have an impact on the type of care required. A possible consequence of dementia for people for whom English is not their first language is reverting to their mother tongue. This must be taken in to consideration, and the relevant translation support put in place if necessary.

How to put the top tip into practice?

• Consider staff training around supporting people with a learning disability who have dementia.

• Think about the importance of the physical environment – 'dementia friendly' environments are often 'learning disability friendly' too.

Resources:

• 'Learning disabilities and dementia', Alzheimer's Society - (https://www.alzheimers.org.uk/info/20007/types_of_dementia/37/learning_disabilities_and_dementia)

• 'Dementia and People with Intellectual Disabilities. Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia' British Psychological Society (2015) - (http://www.bps.org.uk/system/files/Public%20files/rep77_dementia_and_id.pdf)

• Virtual Care Home Dementia Services Development Centre, Stirling - (http://dementia.stir.ac.uk/design/virtual-environments)

Ambition 3: Maximising comfort and wellbeing

'My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible'.

'What makes a 'good death' may vary for every individual, but common factors that can contribute to a person having a 'good death', as opposed to a painful or frightening death, include that people are comfortable and relatively free from pain, and in a supported and dignified setting'.

Dr Pauline Heslop, Professor of Intellectual Disabilities Research and Programme Lead, Learning Disabilities Mortality Review (LeDeR)

TOP TIP:
Help the person to understand their illness and symptoms

Why is this top tip important?

- Most people with a learning disability will cope better with change if they understand what is happening.

- Understanding about their illness can help reduce fear of the unknown.

- Understanding that symptoms are caused by illness (which is not the person's fault) can be important and helps the person report any changes in their symptoms / new symptoms.

- Understanding why the treatment is necessary can help people cope with treatment.

An example of what can happen if someone doesn't understand their symptoms:

'Sally (not her real name) had autism and a mild learning disability. She had bowel cancer and was admitted to a hospice for end of life care. She was not told the truth about her cancer and dying until her final weeks.

When Sally was hardly able to stand up without support, it was clear to everyone that she would not be able to go back to her flat. Sally's desire to go back to her flat dominated my visits during the ensuing months. Nobody acknowledged with her that she would never be able to go back home. Her stepmother told her that she could go back when she was stronger, and the hospice staff went along with this, cheerfully encouraging her to do her exercises and build up strength. However, Sally struggled with the realisation that all these exercises did not have the desired result – to help her become stronger so she could return to her flat. Sally became increasingly distressed, crying frequently, repeating 'I can't walk; I can't move my legs'. She finally worked out for herself that she was dying and wouldn't regain her strength and mobility. Three weeks before she died, she told the nurses, "I am never going to walk again. It is not going to be long." During her final days, she said to her mother, "I think I'm dying mum". The staff and her mother finally acknowledged that she was dying by agreeing with her and Sally was quite peaceful after that.'[22]

Dr Irene Tuffrey-Wijne, Associate Professor, Kingston University

How to put the top tip into practice?

- Staff will need to prepare for having these conversations and need to consider what the person might know already and how to help the person understand what their illness and symptoms will mean for them.

- Having a plan in place to help the person have continued conversations about their illness and symptoms can be really beneficial.

- Staff will need to feel supported themselves in order to have these conversations.

> *'Sometimes people know they are going to die, so find a time to talk. To have that opportunity is important. When it's too late, you are gone'.*
>
> **GRASSroots group**

> *'Tell the person the truth. Even if it's bad news. Don't be frightened'.*
>
> **GRASSroots group**

> *'Don't talk behind my back. Sometimes they talk to my carer and not to me. Or I can hear them talking about me. It's horrible. If you've got something to say, say it to me!*
>
> **GRASSroots group**

> *'No jargon please! There's often a communication breakdown. When you don't understand everything, you feel out of control'.*
>
> **GRASSroots group**

Resources

- Macmillan easy read information about cancer including side effects of cancer treatment, end of life care and a range of other related topics - (http://www.macmillan.org.uk/information-and-support/resources-and-publications/other-formats/easy-read.html)

- Royal College of Nursing easy read leaflets about the management of pain including 'Patient Controlled Analgesia' - (https://www.rcn.org.uk/professional-development/publications/pub-005600) and 'Syringe Pumps For Pain' - (https://www.rcn.org.uk/professional-development/publications/pub-005591)

- 'Am I going to die?' Books beyond words - (https://booksbeyondwords.co.uk/shop/)

TOP TIP:

Support the person to prepare for a visit to hospital or a hospice

Why is this top tip important?

Some people feel afraid about going into hospital or a hospice. If people prefer to be treated in their own homes we need to do all we can to facilitate this. This is particularly so for people with a learning disability, for whom an unfamiliar environment may be especially disturbing. It is also important to consider the spiritual / religious wishes of the person and their family / carers. Many people at the end of life do not wish to be separated from the communities in which they have lived. If a person needs medical intervention or hospice care that cannot be provided at home and the person is fearful about a visit or admission, resulting psychological distress can add to a person's overall level of anxiety. Preparing people for what to expect can help to reduce this anxiety.

How to put the top tip into practice?

- Showing the person around a hospice or hospital can help reduce anxiety about a hospice or hospital admission.

- Inviting the person to see a scanner and/or treatment rooms before their appointment can help reduce fear about medical treatment.

- Using a person centred approach, talking to the person about the upcoming visit and trying to understand their fears will help identify what support the person needs.

- 'Books beyond words' have books about a number of hospital procedures - (https://booksbeyondwords.co.uk/shop/)

- Make use of hospital passports - (http://easyhealth.org.uk/sites/default/files/Hospital%20passport%20-%20JBC.pdf)

A hospital passport is usually a booklet which includes details about the person's likes, dislikes, how best to communicate with the person and other helpful information. Hospital passports can help people with a learning disability provide hospital staff with important information about them and their health when they are admitted to hospital. Hospital passports can be completed and kept at home in case of an emergency admission or deterioration in the person's health, or can be completed prior to a planned admission. Hospital passports are called different names in different areas across the UK; some may be known as the 'traffic light' or 'All about me' documents.

Resources:

- Information for professionals, carers and people with a learning disability about going into hospital. Available from NHS Choices - (http://www.nhs.uk/Livewell/Childrenwithalearningdisability/Pages/Going-into-hospital-with-learning-disability.aspx)

- Information for people with a learning disability about going into hospital. Available from the Health Exchange - (www.healthexchange.org.uk/live-well/going-into-hospital-with-a-learning-disability/)

- 'Working together 2: Easy steps to improve support for people with learning disabilities in hospital.' Available from the national archives - (http://webarchive.nationalarchives.gov.uk/20160704150527/http:/www.improvinghealthandlives.org.uk/gsf.php5?f=313856&fv=21547)

Good practice example

'Mark had a learning disability and a diagnosis of a cancerous tumour on his liver. Whenever Mark was faced with any medical treatment, he experienced severe anxiety and refused treatment. The hospice, palliative care nurse and I worked together with Mark and his family to plan his care. Mark loved art, music and horse riding. We managed to arrange for Mark to visit the local hospice and have regular art sessions (which he called 'pottery'). Attending 'pottery' became a regular routine and we were able to arrange medical appointments to take place between art sessions. He made friends with the nurses at the hospice and was very happy to visit. When the time came for him to stay at the hospice, he was not afraid or anxious, he was going to 'pottery' a place that was special to him and to see people he knew well. His art work was around his room when he died with his family by his side. Mark managed to continue to go to horse riding, art, and dancing right up until the last few weeks, mostly free of pain and making the most of life'.

Denise Souter, Community Learning Disability Nurse, Surrey and Borders NHS Trust

Resources

- Easy read information about their hospitals and services produced by NHS Lanarkshire - (www.healthelanarkshire.co.uk)

- 'Going into hospital' a film produced by The Royal Free London NHS Foundation Trust on behalf of people with a learning disability - (https://www.royalfree.nhs.uk/patients-visitors/disabled-facilities/going-into-hospital-film/)

Be creative in relieving psychological distress and improving wellbeing

Why is this top tip important?

Psychological distress can contribute significantly to a person's overall level of distress, impacting on the person's end of life care experience. By concentrating on ways to relieve psychological distress and improve wellbeing, the overall end of life experience can be improved. As well as being beneficial for the person it also helps family, friends and staff.

How to put the top tip into practice?

- **Maintain connections:** When someone moves to a hospice or nursing home from a residential setting, especially if they have no family relationships, arrange for the person's key worker, or a well-known staff member from the previous home, to spend regular time with the person. If they are well enough time can be spent together engaging in an activity of their choice, for example going 'home' together for an hour or two or out to a favourite place, or just sitting listening to music together, singing, chatting, or watching TV can help improve wellbeing and relieve psychological distress. Arrange for friends to visit and spend time with the person too - this can be forgotten because people often have friends who can't travel without support and it's harder to organise.

- **Maintain normality:** Find out what the person likes to eat and drink and if possible enable them still to enjoy those foods; they might like a glass of beer on a Sunday with their lunch, milky tea at breakfast time, or fish and chips on Fridays. They might smoke, like a walk before bed, watch the 6 o'clock news, or prefer a bath to a shower.

- **Respond to the messages the person gives through their behaviour:** Never assume that if a person cries, shouts, hits out, or behaves in an unusual way it is because of their learning disability. Always try to find out what the person is trying to tell you; are they hot, cold, tired, hungry, frightened, or in pain? Do they need something - a favourite item of clothing or a comforter, do they understand you? Are you approaching them in a way that makes them anxious or scared? Do they need someone that knows them well to be with them?

Mental health problems

People with a learning disability have a higher rate of mental health problems than the general population[23]. Staff should be aware of any mental health problems that exist, for example anxiety and depression and the impact this may have on the person's psychological distress at end of life. Depression and anxiety may be pre-existing or may be triggered at end of life, for example if a person is fearful of death and dying and/or certain treatment, procedures, hospital visits etc.

Resources

- Create a One-Page Profile with the person in preparation for their admission - (http://helensandersonassociates.co.uk/person-centred-practice/one-page-profiles/)

- 'One-page profiles' includes 100 one-page profiles and their stories; from birth to end of life - (https://onepageprofiles.wordpress.com/tag/learning-disability/)

- 'How one-page profiles can help social workers put disabled people in control' Available from the Community Care website - (http://www.communitycare.co.uk/2014/01/03/one-page-profiles-can-help-social-workers-put-disabled-people-control/)

- 'Learning Disabilities, Positive Practice Guide'. Available from the Mental Health Foundation - (https://www.mentalhealth.org.uk/publications/learning-disabilities-iapt-positive-practice-guide)

- 'Depression In People With Intellectual Disabilities', University of Hertfordshire - (http://www.intellectualdisability.info/mental-health/articles/depression-in-people-with-intellectual-disabilities)

A **One-Page Profile** captures all the important information about a person on a single sheet of paper under three simple headings: 'what people appreciate about me', 'what's important to me' and 'how best to support me'. A one-page profile focusing on end of life sums up what things would help the person to feel less anxious and more comfortable in their last few hours, days, weeks and/or months. For example, 'what's important to me' might include enjoying a cup of tea in bed every morning, enjoying spending time with a favourite pet especially stroking them, or having a bubble bath. 'What people appreciate about me' may include things like being funny, friendly and bubbly. 'How best to support me' might include speaking slowly and using 'books beyond words' to help the person understand what is going to happen and putting on a favourite radio station when helping with personal care or providing nursing care.

Good practice examples

'I think the production of an individual's one page profile that shows what a 'normal' day looks like for a person is really important. This can be referred to when someone gets really ill so that a 'normal' day can be facilitated as much as possible. So, if a person MUST go into hospital, the hospital room (usually a side room) could be decked out to look as much like the person's own room as possible with the same kind of sounds and music and environment as they are used to. Likewise in a hospice. Different kind of therapies could be used, sensory profiles could be used so that those senses that the person can still engage or those sensory activities that the person enjoys when well could be replicated in hospital. Music playlists, smells, fiddley things, massage etc.'

Barbie Sayers, Community Learning Disability Nurse, Hertfordshire

'Sarah is approaching the end of her life. She has a learning disability and experiences agoraphobia. Sarah lives alone and dislikes other people being around her. She has 24 hour care, with a carer providing 1:1 support. If anyone else enters her space she becomes distressed and screams. It was felt that any hospital admission would lead to unbearable distress. A best interest decision, made with her family, carers and GP, identified that it would be in her best interests for her end of life care to be provided at home, not in hospital, even if this resulted in an acute deterioration in her health and an earlier death. A full plan is now in place and the carers no longer have to face the dilemma of deciding if they should call an ambulance when her health deteriorates. We hope this proactive plan will ensure that when the time comes, Sarah will have a good end of life with minimal distress'.

Hilary Gardener, Strategic Liaison Nurse for Adults with Learning Disabilities – Primary Care

TOP TIP:

Identify distress by comparing the person's current presentation to their baseline

Why is this top tip important?

It is important to have baseline knowledge of the person to help recognise distress. For example, one person may be very quiet and withdrawn when distressed while another may be very vocally and physically expressive.

How to put the top tip into practice?

- People's current presentation often differs from their usual presentation. Ask the person themselves, other residents/friends, and family about their usual presentation.

- Collect and document this information before a person becomes unwell.

- Use the 'Disability Distress Assessment tool' (DisDAT) – see below.

- When a person whom you don't know is transferred into your care (or when handing over to somebody else), try to find out as much as you can about their baseline expression of discomfort or distress so that you can quickly pick this up before it escalates.

Resources:

The Disability Distress Assessment Tool (DisDAT) is a method of recording a baseline of signs and behaviours when a person is content, against which changes can be monitored when the person is distressed. It is particularly useful for people who do not use speech to communicate. Changes in the person's normal behaviours may indicate a physical, social, emotional or other problem, which will need further investigation - (www.stoswaldsuk.org/how-we-help/we-educate/resources/disdat/disdat-tools.aspx)

TOP TIP:

Carry out an effective and appropriate person centred pain assessment. Ways of assessing pain for the general population may need to be adapted for people with a learning disability where communicating pain verbally may be difficult

Why is this top tip important?

People who have a learning disability may have difficulty reporting and describing pain. Evidence has demonstrated that people with a learning disability are less likely to receive analgesia than people in the general population with the same condition. This inequality is unacceptable. It is essential that appropriate pain assessments are carried out so pain relief can be put in place.

'If you have big certificates [qualifications] it doesn't mean you know the person. If they didn't believe I was in pain, I'd feel upset; I'd feel annoyed as well. You'd feel betrayed, like you were wasting your time going to the doctor. Sometimes they don't believe you'.

GRASSroots group

How to put the top tip into practice?

- There are a number of tools that can support health professionals identify pain in people with a communication difficulty and/or cognitive impairment that are appropriate to use with people who a learning disability.

- Non-verbal communication is really important – a person may tell you they are not experiencing pain but their posture and facial expressions may communicate something different.

- Ensuring that the person's baseline presentation is understood and recorded helps staff to identify if the person is experiencing pain.

- Ensuring that a person's usual 'pain behaviour' is understood and recorded is also helpful so this can be recognised at end of life.

Resources:

- Abbey Pain Scale, Abbey J, De Bellis A, Piller N, Esterman A, Giles L, Parker D. and Lowcay B. Available from Portsmouth Hospitals NHS Trust website - (http://www.porthosp.nhs.uk/Learning/HCSW/palliative/Use_of_the_Abbey_Pain_Scale.pdf)

- 'My pain profile' is a simple two-page record for baseline profile, along with details of medication, possible causes of pain and things that may help them to be more comfortable. This is used alongside a simple two-page assessment to help identify any changes to help identify when an individual mage be in pain . Available from Dying Matters - (www.dyingmatters.org/gp_page/end-life-care-adults-learning-disability)

- 'Do you recognise pain in someone with a learning difficulty and dementia? A Guide for GPs'. Joseph Rowntree Foundation - (www.jrf.org.uk/report/do-you-recognise-pain-someone-learning-difficulty-and-dementia)

Good practice example

Pain pictures using the Abbey Pain Scale:

'It can be difficult for health professionals to identify if a behavioural response like crying is usual for a person who has a learning disability, especially those with complex communication needs. 'Pain pictures' are a traffic light tool based on the Abbey Pain Scale. Pain pictures use the knowledge of those who know a person well, to create a unique profile which identifies the person's usual presentation, when they are well and not in pain, using the categories of the Abbey Pain Scale. For example for 'facial expression', an observation of the person might be 'Always smiling, mouth is naturally turned up at the corners, slightly pink cheeks, pink lips and eyes sparkle'. The next recording identifies observations of how the person has presented when considered to be experiencing pain in the past. For example for 'facial expression' the observation might say 'Becomes flushed, eyes look sad (sometimes closed as if asleep) with blue shadows underneath, looks tired and drawn. Ears also look very red.' The final part of the pain picture identifies interventions and treatment known to be helpful'.

Gweneth Moulster, Consultant Learning Disability Nurse

For further information see Moulster G & Jones M (2015)[24] or email Gweneth Moulster, Consultant Learning Disability Nurse at hefgwen@gmail.com

Ambition 4: Care is coordinated

'I get the right help at the right time from the right people. I have a team around me to who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night'.

TOP TIP:
Involve the person and families/friends/supporters and the person's usual paid carers as partners in care (see ambition 1)

TOP TIP:
Ensure the person's end of life care preferences and needs are recorded in electronic records to facilitate access by all those involved in their care and support. The GP should complete the end of life planning section in the GP Health Check Action Plan following the Annual Health Check which will link to the Summary Care Record. Where available, preferences should also be recorded in Electronic Palliative Care Coordination Systems (EPaCCS)

GP Health Check Action Plan following the Annual Health Check

The recently published 'Annual Health Check for people with a learning disability national template for GP practices' provides a Health Check Action Plan following the Annual Health Check. The action plan includes a section specifically relating to end of life planning. Individuals and carers can ask the GP to add information to the plan including actions the GP will be taking. For further information see 'A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability' . Available from the RCGP website -
(http://www.rcgp.org.uk/clinical-and-research/a-to-z-clinical-resources/learning-disabilities.aspx)

The **Summary Care Record (SCR)** 'holds important information about current medication, allergies and details of any previous bad reactions to medicines and the name, address, date of birth and NHS number of the patient[25]. The SCR is created from GP medical records, available nationally and can be seen and used by authorised staff in other areas of the health and care system involved in the patient's direct care. The patient can also choose to include additional information in the SCR. Additional information may include details of long term conditions, specific communications needs and end of life care preferences'. NHS Digital (2017). Details from the 'GP Health Action Plan' will also link to the SCR.

For example, should a person's end of life care preferences need to be accessed when a person becomes medically unwell and requires an urgent inpatient admission in a part of the country, away from their home location and GP, their preferences could be accessed easily by hospital staff (as long at the enhanced function on the SCR has been turned on by the GP and end of life care preferences have been recorded). However, the SCR cannot be 'over written' so, for example, if the person's wishes changed, the hospital staff would be unable to alter the recorded preferences directly and would need to ask the GP to make the necessary changes.

Electronic Palliative Care Coordination Systems (EPaCCS) enable the recording and sharing of people's end of life care preferences and key details about their care with those delivering their care across organisational boundaries. The systems support coordination of end of life care and the delivery of the right care, in the right place, by the right person, at the right time[26]. National End of Life Care Intelligence Network (2014). EPaCCS is not yet available everywhere but if it is available it should be used.

Why is this top tip important?

Details about a person's end of life care preferences (including the ACP) should be added to the person's electronic care records. This enables clinicians to be aware of any end of life preferences when providing end of life care. This is essential for everyone, including people with a learning disability.

'Hospitals should put information about your learning disabilities on their computer'.

GRASSroots group

How to put the top tip into practice?

- Following the completion of the 'Annual Health Check for people with a learning disability' the GP completes the electronic 'GP Health Action Plan', which contains a section on end of life planning.

- Everyone has a GP Summary Care Record (SCR) and end of life care preferences can be added here by the GP. The 'GP Health Action Plan' also links to the SCR.

- Electronic Palliative Care Co-ordination Systems (EPaCCS) are the preferred way to record end of life preferences for the general population and well known by staff working in palliative and end of life care services. Preferences should be recorded here if EPaCCS is available. However not all areas have EPaCCS in place yet and the different systems in use do not currently 'talk to one another'.

  An advantage of using EPaCCS over the SCR is that information on EPaCCS can be overwritten. For example if a person's end of life preferences are recorded by a community palliative care nurse in London, following a home visit on a local EPaCCS, and the person is later admitted to a hospital for end of life care and the hospital uses the same system, the hospital staff can not only read the person's end of life preferences but also overwrite or add to these are required, in line with the patient's wishes. This is done directly, without the need for the GP.

- NHS Digital is working towards better interoperability (where different computer systems 'talk to each other'), where recording 'end of life care' preferences in one system will populate end of life care preferences in another.

TOP TIP:

Coordinate the involvement of staff from different organisations (and also the involvement of staff within the same organisation)

Why is this top tip important?

> *'Too many people can be overwhelming. Not only that... They can make a fuss. I don't want that. I need time to process things'.*
>
> **GRASSroots group**

> *'Maybe if you have a good friend or family, they could say you don't want too many visitors'.*
>
> **GRASSroots group**

How to put the top tip into practice?

'There will be many people involved in the support for someone with complex health needs at the end of life. It is vital that one named person coordinates this care, and ensures that all the team, including family carers, are fully aware of the stages and action plans. The allocated palliative nurse did this with our team and included GP, ambulance and all paramedic staff. This proved very valuable in times of crisis and made our support network much more efficient and effective'.

Jean Willson OBE, highlighting the importance of coordination in her daughter Victoria's end of life care

The NICE Quality Standard for End of Life Care (2011, updated 2017[27]) includes recommendations around the coordination of end of life care. Special thought will be required to ensure people with a learning disability have equal access to coordinated services across day and night.

- Commissioners and providers will need to ensure that end of life and palliative care (including specialist palliative care and urgent care) is available at any time of day or night.

- Good communication across professionals, settings, daytime and out-of-hours services is essential. Practitioners must be aware of the person's current medical condition, care plan and preferences in order to deliver safe and effective care.

- Everyone involved should know where the end of life preferences are recorded in the end of life planning section in the GP action plan, the Summary Care Record (SCR) or Electronic Palliative Care Coordination Systems (EPaCCS). Preferably, make use of standardised documentation which is agreed locally.

- Having a 'key worker' or small number of named workers can help to coordinate a person's palliative and end of life care, promoting continuity, and ensuring the person and their families and carers, have a named person to access for information and advice.

In addition:

- Keep a contact sheet containing all the telephone numbers of people you may need to contact and ensure this is shared with the team, including the person and family.

- Be fully aware of any Advance Care Plans in situ, e.g. Do Not Attempt CPR.

Resources

- NICE Quality Standard 'End of Life Care'. Statement 8 'Coordinated Care' NICE - (https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-8-Coordinated-care)

- 'Dying well at home: the case for integrated working. Coordinated care: health and social care and housing'. Social Care Institute for Excellence - (http://www.scie.org.uk/publications/guides/guide48/coordinatedcare.asp)

Good practice example

'I worked with a man in his mid-forties who had Downs Syndrome and oesophageal cancer. He lived in his own flat with two hours support a day to assist him with meal preparation and paying bills. He was not able to understand his diagnosis but knew he was having problems eating and drinking and accepted staff support with this. The main area that caused him distress was the sudden onset of seven professionals (palliative care nurse/community learning disability nurse/district nurse/speech and language therapist/GP/consultant psychiatrist/dietician) who each wanted to visit him weekly to assess his progress. He just wanted to continue his normal routine of making model planes and became distressed that these professionals, whom he didn't know, wanted to come in and out. As a group of professionals we all agreed to rotate the visits. We agreed that only one of us would visit and would then share the progress report with the other six. This required professional trust across the disciplines. This worked well and all agreed this was in the best interests of the person. This immediately relieved his distress and allowed his normal routine to continue. The seven professionals were available for the care staff to discuss their concerns and seek advice from and we spent time agreeing on a speciality for each of us so that care staff were able to work out who was the most appropriate person to call for advice'.

Louise Jenkins, Strategic Liaison Nurse for Secondary and Tertiary Care, Hertfordshire

TOP TIP:

When commissioning end of life care for people with a learning disability, include the use of local/voluntary/third sector services as well as NHS and social care services (also see ambition 6)

Why is this top tip important?

People with a learning disability often have complex needs which require the collaborative efforts of health and social care services. Voluntary and third sector services often make significant contributions in providing care, support and advocacy. Utilising voluntary sector expertise can also assist providers of end of life care to meet the cultural and faith related needs of people with a learning disability as well as providing emotional support. This enables a greater say in service care delivery for people from minority ethnic backgrounds with a learning disability and their carers. It is important that commissioners consider the range of people and organisations that are involved in care of people with learning disability, especially towards the end of their lives, and ensure that commissioning strategies take these into account.

How to put the top tip into practice?

- Map out the range of local voluntary and third sector organisations that are accessible in your area.

- Recognise that these organisations can bring different perspectives, skills and expertise to the table.

- Engage these organisations in discussions involving the statutory health and social care organisations in designing and planning end of life care for people with a learning disability.

- Develop relationships with hospice services, inpatient units, outpatient services, day hospice services and community hospice services.

- Joined up thinking between social care services and NHS Continuing Healthcare services providing care is essential. Funding and commissioning challenges are often the reason people with a learning disability have to move out of their (social care) homes.

Resources

- Marie Curie blog about the importance of the voluntary sector in end of life care. Available from the Nuffield Trust website - (https://www.nuffieldtrust.org.uk/news-item/the-voluntary-sector-ready-willing-and-able)

- Cruse Bereavement - A case study in providing effective support to people with a learning disability - (https://www.ncbi.nlm.nih.gov/pubmed/16507032)

Ambition 5: All staff are prepared to care

'Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care'.

TOP TIP:

Support staff and build resilience

Why is this top tip important?

Caring for an individual in their last weeks, days and hours can be distressing and emotional. Many staff will have supported the person for a number of years and formed a close relationship with them. Staff may have known the person for years and feel 'I have to cope'. Staff need to be prepared for this type of work and receive good support. If they do not they risk 'burn out'.

How to put the top tip into practice?

• Staff will need to be aware of what it means for them, when a person they are working with is dying, which may have a real impact on them, especially if they have worked with the person for some time.

• Education and training, commensurate with their roles, need to be provided to ensure that staff can feel confident, and are competent, in delivering care and support.

• Ensure staff have their own support systems in place.

• Have regular team meetings and give support staff time and opportunity to discuss their own fears and concerns.

• Ensure that staff have access to regular, good quality supervision.

• Ensure staff have support following the death of the person to help with their grieving process.

Resources:

• 'The route to success in end of life care - achieving quality for people with learning disabilities'. Chapter: 'Delivery of high quality care in the settings in which people with learning disabilities live', NHS England National End of Life Care team - (http://webarchive.nationalarchives.gov. uk/20130718121128/http:/www.endoflifecare.nhs.uk/search-resources/resources-search/publications/ imported-publications/route-to-success-the-key-contribution-of-nursing-to-end-of-life-care.aspx)

• Royal College of General Practitioners' Autism and learning disability resources - (www.rcgp.org.uk/asd)

• Dying Matters tools for GPs and associated healthcare professionals. These can be adapted for use in your own area . Available from Dying Matters - (www.dyingmatters.org/gp_page/end-life-care-adults-learning-disability)

Good practice example

'Give staff escape options. Sometimes staff will feel very stressed; sad or even cannot continue supporting someone who is near the end of life. As my daughter Victoria approached the end of her life, staff were given the opportunity to work with the other tenant when things became too stressful for them. Some staff were transferred to another house within the organisation'.

Jean Willson OBE

TOP TIP:

Cross sector training will be required to ensure staff working in specialist learning disability services have access to palliative and end of life care training and that those working within palliative and end of life care services receive learning disability training

Why is this top tip important?

In order to provide good quality end of life care it is useful for those who are supporting people with a learning disability at end of life to have some skills in both palliative and learning disability care, to maximise the impact of care.

How to put the top tip into practice?

- It is helpful for palliative care services, hospices, local learning disability services and providers to think about ways of delivering training together, rather than working independently of one another.

- Have local reciprocal arrangements in place where hospices and palliative care services and learning disability services provide training to each other.

Good practice examples

'In January 2017 The Hospice of St Francis, in collaboration with Hertfordshire County Council, Hertfordshire Care Providers Association, Isabel Hospice, Rennie Grove Hospice Care and Garden House Hospice Care began a pilot End of Life Palliative Care Education Programme in two Hertfordshire supported living homes for those adults with a learning disability. The learning disability senior staff and end of life palliative care team worked together to deliver the programme.

The education programme focused on training and supporting staff in two local supported living environments to deliver a hospice model of palliative care to residents in their care. The aim of the programme was to reduce the number of inappropriate hospital admissions of service users and to increase the confidence and competence of the staff in delivering end of life care.

Staff from both care homes attended a two and half day workshop between January and March. As a result of the training, 80% of the care home staff felt that they had greater knowledge and skills in end of life care and 77% felt it has, or will make a difference to the care that they give. Outcomes around inappropriate admissions will be collected at the six month period.

The training has helped staff to recognise that the last days of life are imminent and to feel confident in putting a care plan in place based on an individual's needs in what can often be a complex situation'.

For further details please email Karenann Spicer, Director of Education and Research at the Hospice of St Francis Karenann.Spicer@stfrancis.org.uk

The Croydon CCG and St Christopher's Hospice Partnership Project involves working alongside the Learning Disability Community Health Team and other healthcare professionals. The project aims to develop the knowledge and skills of staff working in 20 care homes in providing palliative care. It does not focus on just the last year of life, more on looking at and planning for the person's current health needs and observing for changes and decline in the physical and mental health of the person and overall wellbeing. This includes planning for end of life care. This project is based on the Steps to Success Programme for End of Life Care (www.stchristophers.org.uk/care-homes/residential-care-homes) which has been adapted for use in learning disability homes to better suit their context and residents' needs.

TOP TIP:

Ensure ALL staff groups have an awareness that those with a learning disability may require reasonable adjustments to achieve a good end of life care experience

Why is this top tip important?

All staff groups and sectors that come into contact with a people who have a learning disability at end of life should have an awareness of the reasonable adjustments that may be required to ensure good end of life care for this population. Without this, people with a learning disability will continue to face an inequality in their end of life care experience, compared to the general public. Commissioners, providers and staff have a duty to make reasonable adjustments to enable people with a disability to equitably access services under the Equality Act (2010) (https://www.gov.uk/guidance/equality-act-2010-guidance).

How to put the top tip into practice?

• Those working in palliative care and in learning disability settings will need to reach out to other staff groups/sectors to support them to develop their awareness about the end of life care needs of people who are dying and have a learning disability.

• During a recent NHS England workshop focusing on end of life care for people with a learning disability, participants identified a range of staff groups who are not always offered education or awareness raising in this area including; GPs, social workers, social services, care home sector, community district nurses and general community nursing teams, health and wellbeing boards, local authority, social services and social care. Education for these groups should be considered as well as for those working in learning disability or palliative care services.

• A lead or champion in each of these staff groups across each CCG area was also identified as useful to support the spread of good practice.

'We assume most people with learning disabilities are living in learning disability services or with their families. However, many are also living in other types of care homes. The research 'Hidden lives and deaths: the last months of life of older people with learning disabilities living in long term care settings for older people in England and Wales', is currently being carried out by University of South Wales in collaboration with University of Southampton, University of Lancaster and Trinity College Dublin (currently unpublished) to identify the characteristics of people with learning disabilities living in generic long term care settings and their end of life care needs. The research indicates that there is a hidden group of people with a learning disability who may experience the end of their lives in generic, long term care homes. In order to improve care in these areas, the needs of people with a learning disability and the needs of those who support them, in this care sector need to be highlighted. These settings may be providing a substantial level of end of life care to this population but we seldom think about their needs or the expertise they might have developed[28]'

Dr Stuart Todd, South Wales University

Resources

• Further information around reasonable adjustments - (http://webarchive.nationalarchives.gov.uk/20160704145719/http://www.improvinghealthandlives.org.uk/projects/reasonableadjustments)

TOP TIP:

Staff need to have excellent communication skills and really adapt these to the needs of the people they support

Why is this top tip important?

A person with a learning disability may find it difficult to understand, process and communicate information. However, as we have seen from ambitions 1 and 3, it is really important that the person is supported to understand what is happening and also express their preferences for their care in the last days/weeks/months of life. People for whom English is not their first language may require translation support/services. Staff working with a person with a learning disability who is dying will need to be especially skilled to support the person well.

How to put the top tip into practice?

- See Ambition 1

- See Ambition 3

- Don't be afraid of using clear and direct language to help the person understand they are dying. For example use 'death' and 'dying' rather than euphemisms like 'passed away' and 'lost' as they can come across as abstract and difficult to understand.

- Staff should support the communication process by using a range of formats for example, easy read documents and picture books such as 'books beyond words'.

Ambition 6: Each community is prepared to help[29]

'I live in a community where everybody recognises that we all have a role to play in supporting each other in a time of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways'.

TOP TIP:

Ensure people with a learning disability are considered to be a part of the local community

Why is this top tip important?

It is important for people with a learning disability to be able to access the range of palliative, end of life and bereavement services available in local communities. Some services may need to provide specialist support for those with a learning disability. However, many people with a learning disability should be able to access mainstream services.

How to put the top tip into practice?

- End of life/palliative care/bereavement charities can become more inclusive to people with learning disabilities by undertaking some learning disability awareness training.

- With some training or information, non-learning disability specific charities can successfully adapt what they do, to meet the needs of people who have a learning disability.

- Ensure people with a learning disability are considered part of the community, e.g. when local directories of resources are collated, make sure that these include resources which address the needs of people with a learning disability and end of life care.

- Use public health approaches to end of life and palliative care which are inclusive of people with a learning disability.

- Include faith groups and faith leaders in planning end of life care support that can be offered in local communities.

Resources:

- Cruse Bereavement - A case study in providing effective support to people with a learning disability - (https://www.ncbi.nlm.nih.gov/pubmed/16507032)

- 'How hospices can develop community approaches which include people with learning disabilities' (chapter 2) . Available from the National Council for Palliative Care (NCPC) - (http://www.ncpc.org.uk/sites/default/files/J1448%20ncpc_strand_6_ART_NC.pdf)

- 'Public Health Approaches to End of Life Care'. A toolkit from Public Health England - (http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf)

- Charter for compassionate communities. Available from Charter for Compassion - (https://charterforcompassion.org/index.php/communities)

- Public Health England (2016) Faith at end of life, A resource for professionals, providers and commissioners working in communities (https://www.gov.uk/government/publications/faith-at-end-of-life-public-health-approach-resource-for-professionals)

TOP TIP:

Encourage discussion around death and dying amongst everyone, not just people with a learning disability

Why is this top tip important?

Promoting openness about death and dying with people who have a learning disability can only happen when the local community, including the friends, family and staff supporting people with a learning disability, feel comfortable talking about death and dying. Society's reluctance to talk about dying makes it much more difficult for people with a learning disability, as it means families and support staff tend to not talk about dying with them.

How to put the top tip into practice?

- Participating in 'Dying Matters' week is one way to raise awareness about death and dying in your area/organisation.

- Be open about your experience of preparing for end of life and any experience of bereavement with colleagues and in your local community.

Resources:

- The Dying Matters coalition aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. Their website includes ideas and resources for raising awareness around death and dying - (http://www.dyingmatters.org/AwarenessWeek)

- Kingston University and St George's University of London, in collaboration with University of South Wales, Glasgow Caledonian University, and University of Ulster are currently undertaking a UK-wide 'Talking About Dying' survey, to find out how widespread the practice of 'not talking about dying' is within learning disability services. This should hopefully help to address the issues. There is no web-link to the study, but there's a twitter conversation #TalkingAboutDyingSurvey

- 'Investigating the factors that affect the communication of death-related bad news to people with intellectual disabilities by staff in residential and supported living services: An interview study' available from the Journal of Intellectual Disability Research - (http://onlinelibrary.wiley.com/doi/10.1111/jir.12375/full)

- 'Why should we develop compassionate communities' from the Dying Matters Coalition includes tips from on how best to engage the community sector on raising awareness around death and dying in your community - (http://www.dyingmatters.org/sites/default/files/user/documents/Resources/Community%20Pack/1-Introduction-1.pdf)

- 'Compassionate Communities North West' from the Compassionate Communities website includes end of life care, death and dying in their compassionate communities - (http://compassionatecommunitiesnw.com/services/)

TOP TIP:

Involve charities / voluntary sector and understand their offer

Why is this top tip important?

'Social value is an approach to commissioning which recognises the additional social, economic and environmental benefits to local communities over and above the direct purchasing of goods, services and outcomes. Levering most value for money from public spending by realising additional benefits from providers at no extra cost generates maximum benefit for the community… which shifts the focus from the cost of a service to the overall value of the outcomes delivered'.

Voluntary Organisations Disability Group (VODG)[30]

How to put the top tip into practice?

- Grow existing volunteer networks drawing on resources/opportunities from both end of life and learning disability services.

- Encourage cross-learning between people with lived experience, and voluntary sector groups from end of life care and learning disabilities, e.g. through joint forums, newsletter presence, etc.

- Encourage voluntary sector groups focusing on end of life care to consider what adjustments might be needed for people with a learning disability, and voluntary sector groups focusing on learning disability to consider the whole of life needs of people with a learning disability, including end of life.

Resources

- Volunteer Management Toolkit, VODG - (https://www.vodg.org.uk/publications/volunteer-management-toolkit/)

- Case studies from across the VODG membership are used to illustrate how not for profit providers add social value, VODG - (https://www.vodg.org.uk/publications/social-value-toolkit/)

How this guide was developed

Stage 1

An NHS England workshop was held in February 2017, attended by experts working in palliative and end of life care. It was supported by; people who had a learning disability from the GRASSroots discussion group, Jean Willson OBE, who shared her daughter's end of life care experience, and representatives from the Palliative Care for People with Learning Disabilities (PCPLD) Network. Participants were asked to consider each ambition and identify which tips, resources and best practice examples would help other clinicians, providers and commissioners achieve the ambitions.

Stage 2

In a joint NHS England and Public Health England webinar on 'Learning Disabilities and End of Life Care' held in March 2017, attended by 240 participants, a call for further additions was made. A recording of the webinar is available (http://www.endoflifecare-intelligence.org.uk/resources/webinar).

Stage 3

An expert reference group then reviewed these suggestions, adding further examples. They also reviewed earlier drafts of the guide. To help us ensure this guide was congruent with the views of people with a learning disability we asked people from the GRASSroots group to comment on what was important to them in end of life care. Their quotes are included throughout the guide.

A number of people from a range of roles helped to develop the guide including:

People with lived experience

• Group for Research Advice, Sharing and Support (GRASSroots group). A group of people with a learning disability based at Generate in South London. The group meet regularly to talk about death and dying, and to support research around death, dying and bereavement. The following members contributed to the development of this guide: Lester Bream, Joanne Burdon, Gary Butler, Patricia Charlesworth, Amanda Cresswell, Antoinette Farrugia, David Jeffrey, Leon Jordan, Michelle McDermott and Carrie Mullinger

• Jean Willson, OBE (who shares the end of life care experience of her daughter Victoria)

Others

• Dr Carole Buckley, Royal College of General Practitioners

• Jason Davidson, Chair Palliative Care for People with Learning Disabilities (PCPLD) Network

• Gemma del Toro, Nottinghamshire Healthcare NHS Foundation Trust

• Kevin Elliott, Learning Disability Programme, NHS England

• Professor Gyles Glover, Public Health England

• Professor Pauline Heslop, The Learning Disabilities Mortality Review (LeDeR) Programme, Bristol

• Anna Marriott, Public Heath England's Learning Disability Observatory

• Gweneth Moulster, OBE, Consultant Learning Disability Nurse

• Clare Price, Project Delivery Manager, End of Life Care Programme

• Barbie Sayers , Community Learning Disability Nurse, Hertfordshire County Council

• Dr Stuart Todd, Reader in Intellectual Disabilities Research, University of South Wales

• Dr Irene Tuffrey-Wijne, Associate Professor, Kingston University

• Professor Bee Wee, National Clinical Director for End of Life Care

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